



# **HIV and Its Treatment: What You Should Know**

*Health Information for Patients*

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## **Fact Sheets**

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# HIV and Its Treatment: What You Should Know

These fact sheets are intended for use by people recently diagnosed with HIV infection or those who are considering starting HIV treatment. The fact sheets are designed as a series but may be used as stand-alone documents. Information in these fact sheets is based on *Guidelines for the Use of Antiretroviral Agents in HIV-Infected Adults and Adolescents*, developed by the Panel on Clinical Practices for the Treatment of HIV Infection, which is convened by the U.S. Department of Health and Human Services (HHS) in conjunction with the Henry J. Kaiser Family Foundation.

The *Guidelines*, which is a "living document," provides updates on new advances in the treatment of HIV. The current version of the document is available on the *AIDSinfo* Web site: <http://aidsinfo.nih.gov/guidelines/>.

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# Testing HIV Positive – Do I Have AIDS?

## I tested HIV positive. What does this mean?

### Does it mean I have AIDS?

A positive HIV test result means that you are infected with HIV (Human Immunodeficiency Virus), the virus that causes AIDS (Acquired Immune Deficiency Syndrome). Being infected with HIV does not mean that you have AIDS right now. However, if left untreated, HIV infection damages a person's immune system and can progress to AIDS.

### What is AIDS?

AIDS is the most serious stage of HIV infection. It results from the destruction of the infected person's immune system.

Your immune system is your body's defense system. Cells of your immune system fight off infection and other diseases. If your immune system does not work well, you are at risk for serious and life-threatening infections and cancers. HIV attacks and destroys the disease-fighting cells of the immune system, leaving the body with a weakened defense against infections and cancer.

### Which disease-fighting cells does HIV attack?

CD4 cells are a type of white blood cell that fights infections. They are also called CD4<sup>+</sup> T cells or CD4 T lymphocytes. A CD4 count is the number of CD4 cells in a sample of blood.

When HIV enters a person's CD4 cells, it uses the cells to make copies of itself. This process destroys the CD4 cells, and the CD4 count goes down. As you lose CD4 cells, your immune system becomes weak. A weakened immune system makes it harder for your body to fight infections and cancer.

### How will I know if I have AIDS?

AIDS is not a diagnosis you can make yourself; it is diagnosed when the immune system is severely weakened. If you are infected with HIV and your CD4 count drops below 200 cells/mm<sup>3</sup>, or if you develop an AIDS-defining condition (an illness that is very unusual in someone who is not infected with HIV), you have AIDS.

## What are the AIDS-defining conditions?

In December 1992, the Centers for Disease Control and Prevention (CDC) published the most current list of AIDS-defining conditions\*. The AIDS-defining conditions are:

- Candidiasis
- Cervical cancer (invasive)
- Coccidioidomycosis, Cryptococcosis, Cryptosporidiosis
- Cytomegalovirus disease
- Encephalopathy (HIV-related)
- Herpes simplex (severe infection)
- Histoplasmosis
- Isosporiasis
- Kaposi's sarcoma
- Lymphoma (certain types)
- Mycobacterium avium complex
- Pneumocystis carinii/jiroveci pneumonia
- Pneumonia (recurrent)
- Progressive multifocal leukoencephalopathy
- Salmonella septicemia (recurrent)
- Toxoplasmosis of the brain
- Tuberculosis
- Wasting syndrome

People who are not infected with HIV may also develop these diseases; this does not mean they have AIDS. To be diagnosed with AIDS, a person must be infected with HIV.

## What is HIV treatment?

HIV treatment is the use of medications to keep an HIV infected person healthy. Treatment can help people at all stages of HIV disease. Although anti-HIV medications can treat HIV infection, they cannot cure HIV infection. HIV treatment is complicated and must be tailored to you and your needs.

The Fact Sheets in this series provide information about HIV treatment, including when to start medication, which medications are used, how to know if treatment is working, and what can be done if your treatment is not working.

## For more information:

Contact your doctor or an *AIDSinfo* Health Information Specialist at 1-800-448-0440 or <http://aidsinfo.nih.gov>.

\* CDC. 1993 Revised classification system for HIV infection and expanded surveillance case definition for AIDS among adolescents and adults. MMWR 1992;41(no. RR-17).

# Seeing an HIV Doctor

## I am HIV positive. What kind of doctor do I need?

Your doctor (or other healthcare provider) should be experienced in treating HIV and AIDS. You may want to see an infectious disease specialist. You will need to work closely with your doctor to make informed decisions about your treatment, so it is important to find a doctor with whom you are comfortable.

## What can I expect at the doctor's office?

Your doctor will ask you questions about your health, do a physical exam, and order blood tests. This is a good time to ask your doctor questions. Write down any questions you have and take them with you to your appointment.

Women should have a pregnancy test (see [HIV and Pregnancy Fact Sheet](#)) and a gynecologic examination with Pap smear.

## What questions should I ask my doctor?

You should ask your doctor about:

- Risks and benefits of HIV treatment
- Other diseases you may be at risk for
- How your lifestyle will change with HIV infection
- How you can avoid transmitting HIV to others
- How you can achieve and maintain a healthier lifestyle

## What tests will my doctor order?

It is very important to have a CD4 count and a viral load test done at your first doctor's visit. The results will provide a **baseline** measurement for future tests.

- **CD4 count** – CD4 cells, also called CD4<sup>+</sup> T cells or CD4 lymphocytes, are a type of white blood cell that fights infection. HIV destroys CD4 cells, weakening your body's immune system. A CD4 count is the number of CD4 cells in a sample of blood.
- **Viral load test** – A viral load test measures the amount of HIV in a sample of blood. This test shows how well your immune system is controlling the virus.

The two viral load tests commonly used for HIV are:

- HIV RNA amplification (RT-PCR) test
- Branched chain DNA (bDNA) test

### Terms Used in This Fact Sheet:

**Baseline:** an initial measurement (such as CD4 count or viral load) made before starting therapy and used as a reference point to monitor your HIV infection.

**Liver function tests (LFTs):** tests that measure the blood levels of liver enzymes (proteins made and used by the liver) to determine if your liver is working properly.

To ensure accurate results, viral load testing should be done at two different times, by the same laboratory, using the same type of test. The results of different types of tests may differ.

Your doctor may also order:

- Complete blood count
- Blood chemistry profile (including **liver function tests**)
- Tests for other sexually transmitted diseases (STDs)
- Tests for other infections, such as hepatitis, tuberculosis, or toxoplasmosis

## Am I ready to begin HIV treatment?

Once you begin taking anti-HIV medications, you may need to continue taking them for the rest of your life. Deciding when or if to begin treatment depends on your health (see [Starting Anti-HIV Medications Fact Sheet](#)) and your readiness to follow a treatment regimen that may be complicated. You and your doctor should discuss your readiness to begin treatment as well as strategies to make your treatment work for you (see [Adherence](#) and [Adhering to a Regimen Fact Sheets](#)).

## If my doctor and I decide to delay treatment, will I need to have my CD4 count and viral load tested again?

Yes. HIV infected people who have not started drug therapy should have a viral load test every 3 to 4 months and a CD4 count every 3 to 6 months. You and your doctor will use the test results to monitor your infection and to decide when to start treatment.

## For more information:

Contact your doctor or an AIDSinfo Health Information Specialist at 1-800-448-0440 or <http://aidsinfo.nih.gov>.

# Starting Anti-HIV Medications

## I am HIV positive. Do I need to take anti-HIV medications?

You do not necessarily need to take anti-HIV (also called **antiretroviral**) medications just because you are HIV positive. You and your doctor will determine the best time to start treatment. When to take anti-HIV medications depends on your overall health, the amount of virus in your blood (**viral load**), and how well your immune system is working.

## How will I know when to start anti-HIV medications?

You and your doctor should consider three factors in deciding when to start treatment: 1) symptoms of advanced HIV disease, 2) viral load, and 3) **CD4 count**.

You should start treatment if:

- you are experiencing severe symptoms of HIV infection or have been diagnosed with **AIDS**
- your viral load is 100,000 copies/mL or more
- your CD4 count is 200 cells/mm<sup>3</sup> or less

You may also consider starting treatment if your CD4 count is between 200 and 350 cells/mm<sup>3</sup>; this is something you should discuss with your doctor.

## If anti-HIV medications can help me stay healthy, why wait to start treatment?

Once you begin treatment, you may need to continue taking anti-HIV medications for the rest of your life. Although newer anti-HIV medications are easier to take, starting treatment usually means a significant adjustment in your lifestyle. Some anti-HIV medications need to be taken several times a day at specific times and may require a change in meals and mealtimes.

In addition to their desired effects, anti-HIV medications may have negative side effects, some of which are serious. If the virus is not suppressed completely, **drug resistance** can develop. Side effects and drug resistance may limit your future treatment options.

### Terms Used in This Fact Sheet:

**AIDS:** Acquired Immune Deficiency Syndrome. AIDS is the most severe form of HIV infection. HIV infected patients are diagnosed with AIDS when their CD4 cell count falls below 200 cells/mm<sup>3</sup> or if they develop an AIDS-defining illness (an illness that is very unusual in someone who is not HIV positive).

**Antiretroviral:** a medication that interferes with replication of retroviruses. HIV is a retrovirus.

**CD4 count:** CD4 cells, also called T cells or CD4<sup>+</sup> T cells, are white blood cells that fight infection. HIV destroys CD4 cells, making it harder for your body to fight infections. A CD4 count is the number of CD4 cells in a sample of blood.

**Drug resistance:** HIV can mutate (change form) while a person is taking anti-HIV medication. This may result in HIV that cannot be controlled with certain medications.

**Viral load:** the amount of HIV in a sample of blood.

## What treatment is right for me?

There are 21 anti-HIV medications approved by the U.S. Food and Drug Administration (FDA) for adults and adolescents. The U.S. Department of Health and Human Services (HHS) provides HIV treatment guidelines to doctors and patients. These guidelines recommend that you take a combination of three or more medications in a regimen called **Highly Active Antiretroviral Therapy** (HAART). The guidelines list "preferred" HAART regimens. However, your regimen should be tailored to your needs. Factors to consider in selecting a treatment regimen include:

- number of pills
- how often the pills must be taken
- if pills can be taken with or without food
- how the medications interact with one another
- other medications you take
- other diseases or conditions
- pregnancy

## For more information:

Contact your doctor or an *AIDSinfo* Health Information Specialist at 1-800-448-0440 or <http://aidsinfo.nih.gov>.



# Recommended HIV Treatment Regimens

## When I start treatment, what kinds of medications will I need to take?

Anti-HIV medications are used to control the reproduction of the virus and to slow the progression of HIV disease. They are also called **antiretroviral** medications. There are four classes of FDA-approved antiretroviral medications: NRTIs, NNRTIs, PIs, and fusion inhibitors. The [Approved Anti-HIV Medications Fact Sheet](#) lists the FDA-approved antiretroviral medications by class.

## How many medications will I need to take?

The recommended treatment for HIV is a combination of three or more medications in a regimen called **Highly Active Antiretroviral Therapy (HAART)**. How many pills you will need to take and how often you will take them depends on what medications you and your doctor choose.

## Which medications should I take?

Each HAART regimen is tailored to the individual patient – there is no one “best” regimen. You and your doctor will decide which medications are right for you. For people taking HAART for the first time, the recommended regimens are:

- Sustiva + (Epivir or Emtriva) + (Retrovir or Viread)
- Kaletra + (Epivir or Emtriva) + Retrovir

## Are there any other treatment regimens?

Some people may benefit from a different regimen. Recommended alternative regimens are:

- Sustiva + (Epivir or Emtriva) + (Ziagen or Videx or Zerit)
- Viramune + (Epivir or Emtriva) + (Retrovir or Zerit or Videx or Ziagen or Viread)
- Reyataz + (Epivir or Emtriva) + (Retrovir or Zerit or Ziagen or Videx) or (Viread + low dose Norvir)
- Lexiva + (Epivir or Emtriva) + (Retrovir or Zerit or Ziagen or Viread or Videx)
- Lexiva + low dose Norvir + (Epivir or Emtriva) + (Retrovir or Zerit or Ziagen or Viread or Videx)
- Crixivan + low dose Norvir + (Epivir + Emtriva) + (Retrovir or Zerit or Ziagen or Viread or Videx)
- Kaletra + (Epivir or Emtriva) + (Zerit or Ziagen or Viread or Videx)
- Viracept + (Epivir or Emtriva) + (Retrovir or Zerit or Ziagen or Viread or Videx)
- Invirase + low dose Norvir + (Epivir or Emtriva) + (Retrovir or Zerit or Ziagen or Viread or Videx)

### Terms Used in This Fact Sheet:

**Antiretroviral:** a medication that interferes with replication of retroviruses. HIV is a retrovirus.

**Drug toxicity:** the harm a medication can do to your body.

**Viral load:** the amount of HIV in a sample of blood.

In general, taking only one or two drugs is not recommended because any decrease in **viral load** is almost always temporary without three or more drugs. The exception is the recommendation for pregnant women, who may take Retrovir alone or with other drugs to reduce the risk of passing HIV to their infants.

If you are pregnant or considering becoming pregnant, there are additional treatment considerations. [HIV and Pregnancy Fact Sheet](#) has more information on HIV treatment and pregnancy.

## What are some of the negative side effects of HAART?

You may experience negative side effects (**drug toxicity**) when you take HIV drugs. Some of these side effects are serious, even life-threatening; you may have to change drugs due to intolerable side effects. You and your doctor or pharmacist should discuss the side effects of each medication.

Possible side effects of HAART include:

- liver problems
- diabetes
- abnormal fat distribution (lipodystrophy syndrome)
- high cholesterol
- increased bleeding in patients with hemophilia
- decreased bone density
- skin rash
- pancreatitis (inflammation of the pancreas)
- nerve problems

Side effects that may seem minor, such as fever, nausea, and fatigue, can mean there are serious problems. Always discuss any side effects you are having with your doctor.

## For more information:

Contact your doctor or an *AIDSinfo* Health Information Specialist at 1–800–448–0440 or <http://aidsinfo.nih.gov>.

# Approved Medications to Treat HIV Infection

Anti-HIV (also called antiretroviral) medications are used to control the reproduction of the virus and to slow the progression of HIV-related disease. Highly Active Antiretroviral Therapy (HAART) is the recommended treatment for HIV infection. HAART combines three or more anti-HIV medications in a daily regimen. Anti-HIV medications do not cure HIV infection, and individuals taking these medications can still transmit HIV to others. Anti-HIV medications approved by the U.S. Food and Drug Administration (FDA) fall into four classes:

Class	Generic Name	Brand & Other Names	Manufacturer	FDA Approval Date
<b>1. Nonnucleoside Reverse Transcriptase Inhibitors (NNRTIs)</b>				
<i>NNRTIs bind to and disable reverse transcriptase, a protein that HIV needs to make more copies of itself.</i>	<b>Delavirdine</b>	Rescriptor, DLV	Pfizer	April 4, 1997
	<b>Efavirenz</b>	Sustiva, EFV	Bristol-Myers Squibb	Sept. 17, 1998
	<b>Nevirapine</b>	Viramune, NVP	Boehringer Ingelheim	June 21, 1996
<b>2. Nucleoside Reverse Transcriptase Inhibitors (NRTIs)</b>				
<i>NRTIs are faulty versions of building blocks that HIV needs to make more copies of itself. When HIV uses an NRTI instead of a normal building block, reproduction of the virus is stalled.</i>	<b>Abacavir</b>	Ziagen, ABC	GlaxoSmithKline	Dec. 17, 1998
	<b>Abacavir, Lamivudine</b>	Epzicom	GlaxoSmithKline	Aug. 2, 2004
	<b>Abacavir, Lamivudine, Zidovudine</b>	Trizivir	GlaxoSmithKline	Nov. 14, 2000
	<b>Didanosine</b>	Videx, ddI, Videx EC	Bristol-Myers Squibb	Oct. 9, 1991 Oct. 31, 2000 (EC)
	<b>Emtricitabine</b>	Emtriva, FTC, Coviracil	Gilead Sciences	July 2, 2003
	<b>Emtricitabine, Tenofovir DF</b>	Truvada	Gilead Sciences	Aug. 2, 2004
	<b>Lamivudine</b>	Epivir, 3TC	GlaxoSmithKline	Nov. 17, 1995
	<b>Lamivudine, Zidovudine</b>	Combivir	GlaxoSmithKline	Sept. 27, 1997
	<b>Stavudine</b>	Zerit, d4T	Bristol-Myers Squibb	June 24, 1994
	<b>Tenofovir DF</b>	Viread, TDF	Gilead Sciences	Oct. 26, 2001
	<b>Zalcitabine</b>	Hivid, ddC	Hoffmann-La Roche	June 19, 1992
	<b>Zidovudine</b>	Retrovir, AZT, ZDV	GlaxoSmithKline	March 19, 1987

## Approved Medications to Treat HIV Infection

Class	Generic Name	Brand & Other Names	Manufacturer	FDA Approval Date
<b>3. Protease Inhibitors (PIs)</b>				
<i>PIs disable protease, a protein that HIV needs to make more copies of itself.</i>	<b>Amprenavir</b>	Agenerase, APV	GlaxoSmithKline, Vertex Pharmaceuticals	April 15, 1999
	<b>Atazanavir</b>	Reyataz, ATV	Bristol-Myers Squibb	June 20, 2003
	<b>Fosamprenavir</b>	Lexiva, FPV	GlaxoSmithKline, Vertex Pharmaceuticals	Oct. 20, 2003
	<b>Indinavir</b>	Crixivan, IDV	Merck	March 13, 1996
	<b>Lopinavir, Ritonavir</b>	Kaletra, LPV/r	Abbott Laboratories	Sept. 15, 2000
	<b>Nelfinavir</b>	Viracept, NFV	Agouron Pharmaceuticals	March 14, 1997
	<b>Ritonavir</b>	Norvir, RTV	Abbott Laboratories	March 1, 1996
	<b>Saquinavir</b>	Invirase, SQV	Hoffmann-La Roche	Nov. 7, 1997 Dec. 6, 1995
	<b>Tipranavir</b>	Aptivus, TPV	Boehringer Ingelheim	June 22, 2005
<b>4. Fusion Inhibitors</b>				
<i>Fusion inhibitors work by blocking HIV entry into cells.</i>	<b>Enfuvirtide</b>	Fuzeon, T-20	Hoffmann-La Roche, Trimeris	March 13, 2003



# Is My Treatment Regimen Working?

## How will I know if my HIV treatment regimen is working?

In general, **viral load** is the most important indicator of how well your regimen is working. Your viral load should decrease if your medications are effective. Other factors that can tell you and your doctor how well your regimen is working are:

- Your **CD4 count**. This should remain stable or go up if your drugs are working.
- Your recent health and results of physical examinations. Your treatment regimen should help keep you healthy.

## How often should I have a viral load test?

Your viral load should be tested 2 to 8 weeks after you start treatment, then every 3 to 4 months throughout treatment to make sure your drugs are still working. HIV treatment should reduce your viral load to the point at which it is undetectable. An undetectable viral load does not mean that your HIV infection is gone; it simply means that the test is not sensitive enough to detect the small amount of HIV left in your blood.

If your viral load is still detectable within 4 to 6 months after starting treatment, you and your doctor should discuss how well you have **adhered** to your regimen (see [Adherence](#) and [Adhering to a Regimen Fact Sheets](#)). Missing medication doses is the most common reason for treatment failure and development of **drug resistance**. Your doctor should do a drug resistance test, which will determine if the HIV in your body has mutated into a strain that your current treatment regimen can't control.

How fast or how much your viral load decreases depends on factors other than your treatment regimen. These factors include your **baseline** viral load and CD4 count, whether you have taken HIV drugs before, whether you have HIV-related medical conditions, and how closely you have followed (adhered to) your treatment. Talk with your health care provider if you are concerned about the results of your viral load tests.

## How often should I have a CD4 count?

CD4 counts also indicate how well your treatment regimen is working. Your CD4 count should be tested

### Terms Used in This Fact Sheet:

**Adherence:** how closely you follow, or adhere to, your treatment regimen. This includes taking the correct dose at the correct time as prescribed by your doctor.

**Baseline:** an initial measurement (such as CD4 count or viral load) made before starting therapy and used as a reference point to monitor your HIV infection.

**CD4 count:** CD4 cells, also called T cells or CD4<sup>+</sup> T cells, are white blood cells that fight infection. HIV destroys CD4 cells, making it harder for your body to fight infections. A CD4 count is the number of CD4 cells in a sample of blood.

**Drug resistance:** HIV can mutate (change form) while a person is taking anti-HIV medication. This may result in HIV that cannot be controlled with certain medications.

**Viral load:** the amount of HIV in a sample of blood.

every 3 to 6 months throughout your treatment. HIV treatment should increase your CD4 count or at least keep it from going down. Talk to your health care provider if you are concerned about your CD4 counts.

## My doctor wants to change my treatment regimen. Why?

There are several reasons why you may need to change your treatment regimen. Two of the most important reasons are *drug toxicity* and *regimen failure*.

*Drug toxicity* means that your treatment regimen creates side effects that make it difficult for you to take the drugs. *Regimen failure* means that the drugs are not working well enough. See [HIV Regimen Failure Fact Sheet](#) for more information about regimen failure.

Ask your doctor to explain why you need to change your treatment. If the reason is drug toxicity, your doctor may change one or more of the drugs in your regimen. If the reason is regimen failure, your doctor should change all of your drugs to medications that you have never taken before. If you have been taking three drugs and all three drugs cannot be changed, at least two drugs should be changed. Using new drugs will reduce the risk of drug resistance. See [Changing Regimens Fact Sheet](#) for more information about changing treatment regimens.

## For more information:

Contact your doctor or an AIDSinfo Health Information Specialist at 1-800-448-0440 or <http://aidsinfo.nih.gov>.

# HIV Treatment Regimen Failure

## What is regimen failure?

Regimen failure occurs when the anti-HIV medications you are taking do not adequately control the infection.

Factors that may cause regimen failure include:

- Poor health before starting the treatment regimen
- Poor adherence to the regimen (not taking medications exactly as instructed by your doctor, including missing doses)
- Previous anti-HIV treatment and/or **drug resistance**
- Alcohol or drug abuse
- Medication side effects, medication **toxicity**, or interactions with other medications
- Medication poorly absorbed by the body
- Medical conditions or illnesses other than HIV infection

## What are the three types of regimen failure?

1. **Virologic failure:** Regimens should lower the amount of HIV in your blood to undetectable levels. Virologic failure has occurred if HIV can still be detected in your blood 48 weeks after starting treatment, or if it is detected again after treatment had previously lowered your **viral load** to undetectable.
2. **Immunologic failure:** An effective regimen should increase the number of CD4 cells in your blood or at least prevent the number from going down. Immunologic failure has occurred if your **CD4 count** decreases below a **baseline** measurement or does not increase above the baseline count within your first year of therapy.
3. **Clinical failure:** Clinical failure has occurred if you experience an HIV-related infection or a decline in physical health despite at least 3 months of anti-HIV treatment.

Virologic failure is the most common kind of regimen failure. People with virologic failure who do not switch to a more effective drug regimen usually progress to immunologic failure within about 3 years. Immunologic failure may be followed by clinical failure.

### Terms Used in This Fact Sheet:

**Baseline:** an initial measurement (such as CD4 count or viral load) made before starting therapy and used as a reference point to monitor your HIV infection.

**CD4 count:** CD4 cells, also called T cells or CD4<sup>+</sup> T cells, are white blood cells that fight infection. HIV destroys CD4 cells, making it harder for your body to fight infections. A CD4 count is the number of CD4 cells in a sample of blood.

**Drug resistance:** HIV can mutate (change form) while a person is taking anti-HIV medication. This may result in HIV that cannot be controlled with certain medications.

**Toxicity:** the harm a medication can do to your body.

**Viral load:** the amount of HIV in a sample blood.

## What happens if my regimen fails?

If your treatment regimen fails, your doctor will evaluate your treatment history, medication side effects, problems you may have had with taking the medications as directed, your physical condition, and results of drug resistance testing to determine why your regimen is failing. You and your doctor may then select a new drug regimen to better control your infection. See [Changing Regimens Fact Sheet](#) for more information about changing treatment regimens.

## For more information:

Contact your doctor or an AIDSinfo Health Information Specialist at 1-800-448-0440 or <http://aidsinfo.nih.gov>.

# Changing My HIV Treatment Regimen

## How will my doctor and I know what medications to use next?

Before changing your treatment regimen, your doctor will try to find out why your current regimen is not working (see [HIV Regimen Failure Fact Sheet](#) for causes of regimen failure). Your doctor will evaluate your *adherence* to the regimen, the regimen's *tolerability*, and *medication interactions*. Whether you and your doctor decide to change your regimen and what new medications you will take will depend on why your current regimen is failing.

## What is adherence?

Adherence refers to how closely you follow (adhere to) your treatment regimen. If your regimen is failing because you cannot adhere to it, you and your doctor should discuss why you are having difficulty taking your medication and what you can do to improve your adherence. Your doctor may change your regimen to reduce the number of pills you take or how often you take them. For more information about adherence, see [Adherence](#) and [Adhering to a Regimen Fact Sheets](#).

## What is tolerability?

Tolerability refers to how many and what types of negative medication side effects you experience. If the side effects are severe, you may need to change your regimen. Your doctor will ask you what side effects you have and how long you have had them. You and your doctor will decide whether to treat the side effects or to change your anti-HIV medications.

## What are medication interactions?

Anti-HIV medications may interact with other medications you are taking. This may reduce the effectiveness of the medications or increase the risk of negative side effects. You and your doctor should review all of your medications, including over-the-counter medications and herbal remedies. You should also review whether your medications should be taken with food or on an empty stomach.

### *Terms Used in This Fact Sheet:*

**CD4 count:** CD4 cells, also called T cells or CD4<sup>+</sup> T cells, are white blood cells that fight infection. HIV destroys CD4 cells, making it harder for your body to fight infections. A CD4 count is the number of CD4 cells in a sample of blood.

**Drug resistance:** HIV can mutate (change form) while a person is taking anti-HIV medication. This may result in HIV that cannot be controlled with certain medications.

**Viral load:** the amount of HIV in a sample of blood.

## Changing Regimens

If your regimen is failing and you and your doctor have ruled out adherence, tolerability, and medication interactions, you should consider changing your regimen. Before changing anti-HIV medications, talk with your doctor about:

- anti-HIV medications you have taken before
- the strength of the new medications your doctor recommends
- possible side effects of the new medications
- how well you will be able to adhere to the new regimen
- the number of anti-HIV medications that you have not yet used

Your doctor will confirm that your regimen is failing with at least two **viral load** tests and three **CD4 counts**. You should also be tested for **drug resistance** while you are taking the failing regimen.

In general, your new treatment regimen should include three or more medications. You and your doctor will choose the medications based on your medication history, results of resistance testing, and medication side effects. If you have already taken many of the FDA-approved anti-HIV medications, your doctor may recommend a new medication under investigation. You may be eligible to participate in a clinical trial using new drugs or treatment strategies. For more information about participating in a clinical trial, ask your doctor, or visit the "Clinical Trials" section of the *AIDSinfo* Web site at: <http://aidsinfo.nih.gov/ClinicalTrials/>.

## For more information:

Contact your doctor or an *AIDSinfo* Health Information Specialist at 1-800-448-0440 or <http://aidsinfo.nih.gov>.

# What is Treatment Adherence?

## What is adherence?

Adherence refers to how closely you follow a prescribed treatment regimen. It includes your willingness to start treatment and your ability to take medications exactly as directed.

## Is adherence important for HIV treatment?

Yes! Adherence is a major issue in HIV treatment for two reasons:

- Adherence affects how well anti-HIV medications decrease your **viral load**. When you skip a medication dose, even just once, the virus has the opportunity to reproduce more rapidly. Keeping HIV replication at a minimum is essential for preventing AIDS-related conditions and death.
- Adherence to HIV treatment helps prevent **drug resistance**. When you skip doses, you may develop strains of HIV that are resistant to the drugs you are taking and even to drugs you have not yet taken. This may leave you with fewer treatment options should you need to change treatment regimens in the future. Because drug-resistant strains can be transmitted to others, engaging in risky behavior can have especially serious consequences.

Although there are many different anti-HIV medications and treatment regimens, studies show that *your first regimen has the best chance for long-term success*. Taking your drugs correctly (adherence) increases your odds of success.

## Why is adherence difficult for many people with HIV?

HIV treatment regimens can be complicated; most regimens involve taking multiple pills each day. Some anti-HIV medications must be taken on an empty stomach, while others must be taken with meals. This can be difficult for many people, especially for those who are sick or are experiencing HIV symptoms or negative drug side effects.

Other factors that can make it difficult to adhere to an HIV treatment regimen include:

- Experiencing unpleasant medication side effects (such as nausea)

### Terms Used in This Fact Sheet:

**Drug resistance:** HIV can mutate (change form) while a person is taking anti-HIV medication. This may result in HIV that cannot be controlled with certain medications.

**Viral load:** the amount of HIV in a sample of blood.

- Sleeping through doses
- Traveling away from home
- Being too busy
- Feeling sick or depressed
- Forgetting to take medications

## What can I do to adhere to my treatment regimen?

There are many things you can do to better adhere to your treatment regimen. [Adhering to a Regimen Fact Sheet](#) discusses what you can do to improve your adherence both before and after you start taking anti-HIV medications.

One of the most important things you can do when starting a treatment regimen is to talk with your doctor about your lifestyle. He or she will then be able to prescribe a regimen that works best for you. Topics you should address with your doctor include:

- Your travel, sleep, and eating schedule
- Possible side effects of medication
- Other medications you are taking and their possible interaction with anti-HIV medications
- Your level of commitment to following an HIV treatment regimen

Many people adhere well to their treatment early on, but find adherence becomes more difficult over time. Talk with your health care provider about adherence during every visit. Your commitment to a treatment plan is critical; studies show that *patients who take their medications correctly achieve the best results*.

## For more information:

Contact your doctor or an AIDSinfo Health Information Specialist at 1-800-448-0440 or <http://aidsinfo.nih.gov>.



# Adhering To My HIV Treatment Regimen

## What should I do before I begin treatment?

Before you begin an HIV treatment regimen, there are several steps you can take to help you with **adherence**:

- Talk with your doctor about your treatment regimen.
- Get a written copy of your treatment plan that lists each medication, when and how much to take, and if it must be taken with food or on an empty stomach.
- Understand how important adherence is (see [Adherence Fact Sheet](#)).
- Be honest about personal issues that may affect your adherence. Adherence may be harder for people dealing with substance abuse or alcoholism, unstable housing, mental illness, or other life challenges.
- Consider a "dry run." Practice your treatment regimen using vitamins, jelly beans, or mints. This will help you determine ahead of time which doses might be difficult to take correctly.
- Develop a plan that works for you.

Many people find it helpful to identify the activities they normally do at the times they will be taking their medication. People who arrange their medication schedule around their daily routines adhere to their treatment plans better than those who do not.

## How can I maintain adherence after I start treatment?

- Take your medication at the same time each day.
- Put a week's worth of medication in a pill box at the beginning of each week.
- Use timers, alarm clocks, or pagers to remind you when to take your medication.
- Keep your medication in the place where you will take it. You may want to keep backup supplies of your medication at your workplace or in your briefcase or purse.

### Term Used in This Fact Sheet:

**Adherence:** how closely you follow, or adhere to, your treatment regimen. This includes taking the correct dose at the correct time as prescribed by your doctor.

- Keep a medication diary. Write the names of your drugs in your daily planner, then check off each dose as you take it.
- Plan ahead for weekends, holidays, and changes in routine.
- Develop a support network of family members, friends, or coworkers who can remind you to take your medication. Some people also find it helpful to join a support group for people living with HIV infection.
- Monitor your medication supply. Contact your doctor or clinic if your supply will not last until your next visit.

## What should I do if I have problems adhering to my treatment regimen?

It is important that you tell your doctor right away about any problems you are having with your treatment plan. If you are experiencing unpleasant side effects, your dose may need to be adjusted or you may need a change in your regimen (see [Changing Regimens Fact Sheet](#) for more information about changing your treatment regimen). Missed doses may be a sign that your treatment plan is too complicated or unrealistic for you to follow. Talk with your doctor about other treatment options. Your doctor needs to stay informed to help you get the most out of your treatment regimen and to provide workable treatment options.

### For more information:

Contact your doctor or an *AIDSinfo* Health Information Specialist at 1-800-448-0440 or <http://aidsinfo.nih.gov>.



# HIV and Pregnancy

## I am HIV positive and pregnant. Should I take anti-HIV medications?

You should take anti-HIV medications if:

- you are experiencing severe symptoms of HIV or have been diagnosed with AIDS
- your **CD4 count** is 200 cells/mm<sup>3</sup> or less
- your **viral load** is greater than 1,000 copies/mL

You should also take anti-HIV medications to prevent your baby from becoming infected with HIV. Specific treatment to prevent **mother-to-child transmission** of HIV is discussed below.

## What medications should I take if I am pregnant or think I might become pregnant?

If you are pregnant or may become pregnant, you should consider the risks and benefits of HIV treatment to both you and your child. Some medications (such as Sustiva) should be avoided because they may cause birth defects if taken early in pregnancy. The effects of other anti-HIV medications are not yet known. It is important for you to talk with your doctor before and during your pregnancy so that together you can decide on the best treatment for you and your baby.

To reduce the risk of passing HIV to your baby, your treatment regimen should include a three-part ZDV (also known as zidovudine, AZT, or Retrovir) regimen.

## I am already on an HIV treatment regimen. Do I need to change my medications?

If you are already taking anti-HIV medications, talk with your doctor about the potential risks and benefits to your baby if you decide to continue your treatment regimen during your pregnancy. You and your doctor may decide to change your medications or change your medication dose. Make sure that your regimen includes the appropriate dose of ZDV.

In general, efavirenz (Sustiva), stavudine (Zerit), hydroxyurea, and the oral liquid form of amprenavir (Agenerase) should not be used during pregnancy.

### Terms Used in This Fact Sheet:

**CD4 count:** CD4 cells, also called T cells or CD4<sup>+</sup> T cells, are white blood cells that fight infection. HIV destroys CD4 cells, making it harder for your body to fight infections. A CD4 count is the number of CD4 cells in a sample of blood.

**Mother-to-child transmission:** also called perinatal transmission. HIV may be passed from an HIV infected mother to her baby during pregnancy or delivery. HIV may also be passed from mother to child through breast milk.

**Viral load:** the amount of HIV in a sample of blood.

## What is the three-part ZDV regimen?

1. HIV infected pregnant women should take ZDV starting at 14 to 34 weeks of pregnancy. You can take either 100 mg five times a day, 200 mg three times a day, or 300 mg twice a day.
2. During labor and delivery, you should receive ZDV intravenously (through an IV in the vein).
3. Your baby should take ZDV (in liquid form) every 6 hours for 6 weeks after he or she is born.

## Will my baby be born HIV infected?

No one can tell you for sure if your baby will be born HIV infected. The three-part ZDV regimen has been shown to reduce the risk of passing HIV to your baby by almost 70%.

Additional anti-HIV medications can treat your infection and may provide extra protection for your baby. However, the possible problems with using multiple medications during pregnancy are not well understood.

Other actions to help you protect your baby include getting regular prenatal care and adhering to your HIV drug treatment plan (see [Adherence](#) and [Adhering to a Regimen Fact Sheet](#)).

AIDSinfo has developed a series of five fact sheets that discuss HIV and pregnancy in more detail. These fact sheets are available at [www.aidsinfo.nih.gov/other/factsheet.asp](http://www.aidsinfo.nih.gov/other/factsheet.asp).

## For more information:

Contact your doctor or an AIDSinfo Health Information Specialist at 1-800-448-0440 or <http://aidsinfo.nih.gov>.

# Understanding HIV Prevention

## **I am HIV positive and don't want to infect others. What should I do?**

Understanding how HIV is transmitted is an important step in prevention. Talk with your health care provider about how HIV is transmitted and what you can do to prevent infecting others. Each time you visit your health care provider, discuss your high-risk behaviors, such as unprotected sex and needle sharing.

You may feel reluctant to talk with your health care provider about your high-risk behaviors. It can be difficult to change behaviors, even when you want to. However, it is important to be honest with your provider about risky activities. You and your provider can then discuss ways to minimize the risk of infecting others.

If you are a woman, you and your doctor should discuss ways to prevent pregnancy. If you want to become pregnant, you and your doctor can talk about what you should do to prevent transmitting HIV to your baby (see [HIV and Pregnancy Fact Sheet](#)).

## **How can I prevent infecting someone else?**

Successful HIV treatment can lower your viral load, which may reduce the risk of HIV transmission. But there are other factors that influence sexual transmission of HIV, such as:

- presence of other sexually transmitted diseases (STDs)
- genital irritation
- menstruation
- lack of circumcision in men
- taking birth control pills
- hormone imbalances
- vitamin and mineral deficiencies

Always use prevention strategies, such as condoms and safer sex practices. If you inject drugs, don't share your works with anyone else. Talk with your health care provider if you have trouble sticking to these prevention strategies. You and your provider can then find ways to make your high-risk behaviors safer.

## **Should I tell my partners that I am HIV infected?**

Yes. It is very important that you tell your sexual partners and people with whom you have shared injected drugs that they may have been exposed to HIV and should be tested. You and your health care provider can discuss the best way to notify your partners. Some health departments and HIV clinics have anonymous partner notification systems—your partners are told that they have been exposed, but are not told who reported their names or when the reported exposure occurred.

It is important to use HIV prevention strategies even if your partner is also HIV infected. Your partner may have a different strain of the virus that could act differently in your body or be resistant to different anti-HIV medications.

## **I am taking anti-HIV medications and my viral load is undetectable. Am I cured? Can I infect others?**

An undetectable viral load does not mean that you are cured. It means that the amount of HIV virus in your blood is so low that the viral load tests cannot detect it. You are still infected with HIV and can infect others. You should continue to use prevention strategies and should see your health care provider regularly.

## **For more information:**

The Centers for Disease Control and Prevention (CDC) National Prevention Information Network (NPIN) provides information about prevention of HIV infection, other sexually transmitted diseases, and tuberculosis.

If you have questions about ways to prevent transmitting HIV, contact your doctor or a CDC NPIN Information Specialist at 1-800-458-5231 or <http://cdcnpin.org>.